

REPORT OF THE  
SURGEON GENERAL'S WORKSHOP ON  
CHILDREN WITH HANDICAPS AND THEIR FAMILI  
CASE EXAMPLE: THE VENTILATOR-  
DEPENDENT CHILD



Presented by the

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service  
Health Resources and Services Administration  
Bureau of Health Care Delivery and Assistance  
Division of Maternal and Child Health

In Conjunction With  
THE CHILDREN'S HOSPITAL OF PHILADELPHIA

DECEMBER 13TH AND 14TH 1982

DHHS PUBLICATION NO. PHS-83-50194

*It is profoundly important for our society that we tend to these issues of disabled children, that these children not be forgotten or pushed aside, and that we retain our belief in the strength of the American family.*

—C. EVERETT KOOP, M.D.  
SURGEON GENERAL

LTD

*The Surgeon General's Workshop  
on Children With Handicaps and Their Families  
was supported by grants from the  
U.S. Department of Health and Human Services,  
The Widener Memorial Foundation, and  
Heron Respiratory Services, Inc.*

Photos Courtesy of The Children's Hospital of Philadelphia

THE WHITE HOUSE

December 10, 1982

Dear Friends:

This brings my special greetings to each of you participating in the Surgeon General's Workshop on Children with Handicaps and Their Families.

I want to encourage you in this very important endeavor. For many children facing physical difficulties, there is no place like home and no substitute for being close to a loving family. I am hopeful that ways can be found to make it possible for many more children on life-supportive devices to go home. It will mean more than we know to both the children and their parents. The entire family will derive untold strength from being together.

I thank you from the bottom of my heart for your interest in helping our special children. You have my warmest best wishes for a successful workshop.

Sincerely,

*Nancy Reagan*

The Surgeon General's Workshop on  
Children with Handicaps and Their Families  
The Children's Hospital of Philadelphia  
Philadelphia, Pennsylvania

## PREFACE

The Surgeon General's Workshop on Children With Handicaps and Their Families recognizes our continuing interest in assisting the family as the prime source of nurture, support, protection, and guidance to the growing child. Children with handicaps and their families frequently require long-term medical, social, educational, vocational, habilitative, and community service assistance. This concept is essential to the provision of comprehensive services to children with special needs.

Families of these children, including siblings, often need significant psychosocial support, but community support services are often lacking or not visible. Without the needed support, the family will have difficulty in helping the child, a growing individual moving through predictable developmental stages, achieve maximum development within the limitations imposed by a disability.

The goal of the participants at this Surgeon General's Workshop was to develop recommendations for strategies to recognize the special burden and challenges borne by the parents and siblings of children with disabilities and to stimulate the provision of resources to safely support these children in their communities. The achievement of this goal will, ideally, minimize the problems of children with disabilities.



C. Everett Koop, M.D.  
Surgeon General



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on Children With Handicaps and Their Families

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# WORKSHOP PROGRAM

**December 13, 1982**

8:00 a.m. - 11:45 a.m.	Plenary Session Joseph Stokes Auditorium The Children's Hospital of Philadelphia
Presiding	Merle G. McPherson, M.D. Chief, Habilitative Services Branch Division of Maternal and Child Health United States Department of Health and Human Services—Public Health Service
Welcome	Noel E. Kroncke, President The Children's Hospital of Philadelphia  Ginny Thornburgh Advocate for the Handicapped  James A. O'Neill, Jr., M.D. Surgeon-in-Chief The Children's Hospital of Philadelphia  Thomas W. Langfitt, M.D. Vice President for Health Affairs University of Pennsylvania  Robert G. Kettrick, M.D. Director, Pediatric Intensive Care Unit Intermediate The Children's Hospital of Philadelphia
8:30 a.m. Keynote and Charge	C. Everett Koop, M.D. Surgeon General
9:00 a.m. Ventilator-Dependent Children: The Problem	Robert G. Kettrick, M.D.
9:45 a.m. The Child at Home	Mrs. Bette Wartenberg Parent of a Ventilator-Dependent Child Joliet, Illinois
10:45 a.m. Comprehensive Regionalized Care: New York Experience	Mathew H.M. Lee, M.D. Professor and Director, Howard A. Rusk Respirator Rehabilitation Medicine Department of Rehabilitative Medicine New York University Medical Center Goldwater Memorial Hospital New York, New York

11:15 a.m. Towards a Consortium: The Illinois Approach	Allen I. Goldberg, M.D. Director, Division of Respiratory Care Children's Memorial Hospital Chicago, Illinois
	Arthur F. Kohrman, M.D., Director LaRabida Children's Hospital and Research Center Chicago, Illinois
	Eugene Bilotti, Administrator Supplemental Security Income (SSI) Disabled Children's Program Springfield, Illinois
11:45 a.m. Question Period	Morning Speakers
12:15 p.m.	Luncheon Salons A and B Hilton Hotel of Philadelphia
Presiding	C. Everett Koop, M.D.
Invocation	The Reverend William Atkinson, O.S.A.
Children with Disabilities— Implications for Care	Alfred Healy, M.D. Chairman, Division of Developmental Disabilities University Hospital School University of Iowa Iowa City, Iowa
2:00 p.m. Background for Work Group Discussion	Phyllis R. Magrab, Ph.D. Director, Child Development Center Georgetown University Hospital Washington, D.C.
2:30 - 5:30 p.m.	Workshops
<b>December 14, 1982</b>	
8:00 a.m.	Work Groups
2:00 p.m. - 5:00 p.m. Plenary Session- Summation	Joseph Stokes Auditorium The Children's Hospital of Philadelphia
Presiding	Robert G. Kettrick, M.D.
Presentations from Work Groups	
Synthesis of Recommendations	John MacQueen, M.D. Director Iowa Specialized Child Health Services University of Iowa Hospitals and Clinics Iowa City, Iowa
Presentation to Surgeon General	Robert G. Kettrick, M.D.
Acceptance of Recommendations	C. Everett Koop, M.D.
Conclusion	Richard D. Wood, Chairman Board of Managers The Children's Hospital of Philadelphia

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